

Prospective Study of Health Status Preferences and Changes in Preferences Over Time in Older Adults

Terri R. Fried, MD; Amy L. Byers, PhD; William T. Gallo, PhD; Peter H. Van Ness, PhD, MPH; Virginia R. Towle, MPhil; John R. O'Leary, MA; Joel A. Dubin, PhD

Background: Instructional forms of advance care planning depend on the ability of patients to predict their future treatment preferences. However, preferences may change with changes in patients' health states.

Methods: We conducted in-home interviews of 226 older community-dwelling persons with advanced cancer, congestive heart failure, or chronic obstructive pulmonary disease at least every 4 months for up to 2 years. Patients were asked to rate whether treatment for their illness would be acceptable if it resulted in 1 of 4 health states.

Results: The likelihood of rating as acceptable a treatment resulting in mild (odds ratio [OR], 1.11; 95% confidence interval [CI], 1.06-1.16) or severe (OR, 1.06; 95% CI, 1.03-1.09) functional disability increased with each month of participation. Patients who experienced a decline in their ability to perform instrumental activities

of daily living were more likely to rate as acceptable treatment resulting in mild (OR, 1.23; 95% CI, 1.08-1.40) or severe (OR, 1.23; 95% CI, 1.11-1.37) disability. Although the overall likelihood of rating treatment resulting in a state of pain as acceptable did not change over time (OR, 0.98; 95% CI, 0.96-1.01), patients who had moderate to severe pain were more likely to rate this treatment as acceptable (OR, 2.55; 95% CI, 1.56-4.19) than were those who did not have moderate to severe pain.

Conclusions: For some patients, the acceptability of treatment resulting in certain diminished states of health increases with time, and increased acceptability is more likely among patients experiencing a decline in that same domain. These changes pose a challenge to advance care planning, which asks patients to predict their future treatment preferences.

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Author Affiliations: Clinical Epidemiology Research Center, VA Connecticut Healthcare System (Dr Fried), Departments of Medicine (Dr Fried) and Epidemiology and Public Health (Drs Gallo, Van Ness, and Dubin), and Program on Aging (Dr Van Ness, Ms Towle, and Mr O'Leary), Yale University School of Medicine, New Haven, Conn; and Department of Geriatric Psychiatry, Weill Medical College of Cornell University, New York, NY (Dr Byers).

PATIENTS WITH DIMINISHED states of health rate these states more highly than does the general public,¹⁻³ and patients with cancer are more willing to undergo intensive therapy with a small likelihood of benefit than are physicians or the general public.^{4,5} These findings suggest that changes in the health status of patients may affect their treatment preferences as they become more willing to tolerate a diminished state of health.⁶ Patients' valuations of health states are likely to be associated with treatment preferences because these preferences are based largely on the outcome achieved by any given intervention.⁷⁻⁹ Changes in treatment preferences as a result of changing health have profound implications for instructional forms of advance care planning, which ask patients their preferences for end-of-life care.

There has been little longitudinal examination of the association between patients' health states and their end-of-life treatment preferences among patients with advanced illness, for whom advance care

planning is most pertinent. Most longitudinal studies of patients' treatment preferences examined preferences for specific interventions without specifying the health states resulting from those interventions.¹⁰⁻¹⁸ These studies, therefore, could not assess whether changes in preferences resulted from changes in patients' valuation of health states. Two studies specifying the health states resulting from intervention,

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one performed in a general population of older persons¹⁹ and the other in persons with AIDS,²⁰ found preferences to be moderately unstable, with no clear associations between preferences and changes in participants' own health.²⁰ This study examined changes over time in end-of-life treatment preferences, measured in terms of willingness to undergo treatment based on the health state that would result from the treatment, in a cohort of older persons with advanced chronic illness.

PARTICIPANTS

Study participants were 226 community-dwelling older persons with advanced chronic illness. The human investigations committee of each of the participating hospitals approved the study protocol, and each participating patient provided written informed consent. We screened sequential medical records of persons aged 60 years or older having a primary diagnosis of cancer, congestive heart failure (CHF), or chronic obstructive pulmonary disease (COPD) for the primary eligibility requirement, advanced illness, as defined by criteria of Connecticut Hospice Inc, Branford, Conn,²¹ or SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment).²² Medical records were identified according to the patient's age and primary diagnosis in the specialty outpatient practices in the greater New Haven area and in 3 hospitals: a university teaching hospital, a community hospital, and a Veterans Administration hospital. Of the 26 practices approached for participation, 3 (12%) did not permit screening of their medical records. An additional eligibility criterion was the need for assistance with at least 1 instrumental activity of daily living (IADL),²³ determined during a telephone screening and selected to improve the identification of patients who had advanced disease.²⁴ Because of our interest in the relationship between disease diagnosis and preferences, screening and enrollment were stratified to enroll approximately equal numbers of patients with cancer, CHF, and COPD.

Of the 548 patients identified by medical record review, 470 patients were screened via telephone; of the remainder, physicians refused permission to call 30 patients, 24 patients died before the call could be made, 18 patients refused screening, and 6 patients could not be reached. Patients who were not screened were significantly older (75 vs 72 years; $P < .001$, t test) but did not differ according to sex or diagnosis. Of those screened, 362 required assistance with IADLs. Exclusion criteria included cognitive impairment in 77 patients and part-time Connecticut residence in 6 patients. Of the 279 eligible patients, 2 died before participation and 51 refused participation, resulting in 226 participants. Nonparticipants did not differ from participants according to age or sex. Of eligible patients with CHF, 8% refused participation, compared with 19% of patients with cancer and 25% of patients with COPD ($P = .02$, χ^2 test). Of the 226 participants, 8 (4%) withdrew after the initial interview, 26 (12%) died before completing a follow-up interview, and 3 (1%) were unable to participate in follow-up interviews. Of the surviving 124 participants at the end of the first year of the study, 98 (79%) consented to a second year of participation.

DATA COLLECTION

We interviewed patients in their homes, obtaining all variables by self-report. We subsequently interviewed patients at least every 4 months for up to 2 years. If the patient experienced a decline in health status, determined during a monthly telephone call, the next interview was scheduled immediately. We then conducted subsequent interviews every 4 months unless the patient experienced another decline in health status. We used this strategy to balance the burden imposed by frequent interviews with the desire to interview patients as their illness worsened but before they died. We defined decline in health status as a new disability in a basic activity of daily living,²⁵ a prolonged hospitalization (≥ 7 days) or a hospitalization resulting in discharge to a nursing home or rehabilitation facility, or introduction of hospice services.

Descriptive and analytic variables included measures of sociodemographic, health, and psychosocial status. Ordinal variables were dichotomized so that at least 10% of respondents were in the category of most severe status. Sociodemographic variables included age and education (continuous variables), sex, race/ethnicity, sufficiency of monthly income,²⁶ marital status, and living arrangement. Health status variables included self-rated health, with response categories of "excellent," "very good," or "good" vs "fair" or "poor"; number of IADL disabilities (range, 0-14); self-rated life expectancy (patients were asked, "If you had to take a guess, how long do you think you have to live?"); and level of pain (patients were asked, "How would you describe your worst pain during the last 24 hours?"), with response categories of "no pain" or "mild pain" vs "moderate pain" or "severe pain." Psychosocial variables included quality of life, with response categories of "best possible" or "good" vs "fair," "poor," or "worst possible"; depression, measured using the 2-item PRIME-MD (Primary Care Evaluation of Mental Disorders) instrument²⁷; and whether the patient had a living will. Health and psychosocial variables were obtained at each interview.

The outcome variables, assessed at each interview, were obtained by asking patients to think about whether 4 health states that could result from treatment represented either an acceptable or unacceptable quality of life. Similar to the concept of "states worse than death,"²⁸ they were told that rating the health state as acceptable meant that they would want to undergo treatment and that rating the health state as unacceptable meant that they would prefer to die rather than undergo treatment. The states included mild physical disability, described as being unable to leave the house to visit family, attend religious services, go to work, do volunteer work, or do hobbies; severe physical disability, described as only being able to get from bed to chair and requiring help with bathing, dressing, and grooming; cognitive impairment, described as having severe problems with memory such that you cannot recognize family members; and pain, described as being in moderately severe pain daily, for example, like having a broken bone or appendicitis. Test-retest reliability was established by reinterviewing 20 participants 1 week after their initial interview. This period was chosen as long enough to decrease the likelihood that participants would remember their initial responses but short enough that they would not undergo a change in health status. Raw agreement for the 4 states was 89%, 80%, 95%, and 87%, respectively, with corresponding κ coefficients of 0.75, 0.58, 0.64, and 0.72. The percentage of respondents rating the second and third states as unacceptable at baseline was high (70% and 95%, respectively), resulting in lower κ coefficients.²⁹ At the baseline interview, the correlation in ratings among the 4 health states was $r \leq 0.43$, except for the 2 disability states, for which the correlation was $r = 0.59$.

STATISTICAL ANALYSIS

To describe the population, we used mean (SD) for continuous variables and frequency and percentage for categorical variables. We defined 5 trajectories for health state ratings over time—acceptable at all times, unacceptable at all times, change from acceptable to unacceptable without further changes, change from unacceptable to acceptable without further changes, and variable (ie, multiple changes in rating). We examined the frequency of these trajectories according to 4 trajectories for functional status over time, defined by the number of IADL disabilities: unchanged, improved, declined, and other (both improvement and decline over time).

To determine factors associated with ratings, we used generalized linear mixed-effects models^{30,31} by imple-

Table 1. Characteristics of 226 Participants at Baseline*

Characteristic	Value
Diagnosis	
Cancer	35
Chronic obstructive pulmonary disease	36
Congestive heart failure	29
Age, mean ± SD, y	73 ± 7
Education, mean ± SD, y	12 ± 3
White race	91
Female sex	43
Married	58
Has a living will	53
Self-rated health: excellent, very good or good	36
Self-rated quality of life: best possible or good	64
Depressed	47
Moderate or severe pain	27
≥2 Hospitalizations in past year	47
Intensive care unit admission in past year	34
Self-rated life expectancy	
<2 y	14
≥2 y	42
Uncertain	44

*Data are given as percentages unless otherwise stated.

menting repeated measures logistic regression with inclusion of a patient-level random effect. We chose the mixed-effects model over a competing approach, for example, a marginal model approach using generalized estimating equations,³² because we wanted to account for irregular interview times and to draw inferences at the subject-specific level. We developed 4 multivariable models, using a forward selection approach, with no correction for multiple comparisons. For each model, the dependent variable was the rating of a given health state as acceptable or unacceptable as a result of treatment at each time point. Independent variables were eligible for inclusion in each of the multivariable models if they were associated with the health state rating in a bivariate model with $P < .20$. To be included in the final model, the variable needed to maintain $P < .10$. In each model we included age, sex, race/ethnicity, marital status, and time, regardless of their bivariate associations. Time was measured in months since the start of the study for each individual. All analyses were carried out using SAS software (version 8.2; SAS Institute Inc, Cary, NC), using PROC NL MIXED to fit the generalized linear mixed-effect models.³³

RESULTS

PATIENT POPULATION

Table 1 provides a description of the patient population. During the 2 years of follow-up, 77% of patients with cancer, 43% of patients with COPD, and 46% of patients with CHF died. Of the cohort, 68% participated in at least 3 interviews and 36% participated in 5 or more interviews. The median number of interviews was 2 for patients with cancer, 4 for patients with CHF, and 5 for patients with COPD. Among nondropouts, ascertainment of outcome data was

90% complete, and of the 10% of missing data, 89% was due to the participant being too cognitively impaired or too ill to participate in the interview.

DESCRIPTION OF TRAJECTORIES OF HEALTH STATE RATINGS

For each of the health states, at least 49% of participants provided the same rating (acceptable or unacceptable) throughout the study (**Table 2**). For the 2 states representing mild and severe functional impairment, larger proportions rated the states as acceptable at all interviews (56% and 32%, respectively) vs unacceptable (8% and 19%, respectively). In addition, a larger proportion of participants changed their ratings from unacceptable to acceptable (19% and 20%, respectively) vs acceptable to unacceptable (6% and 6%, respectively). In contrast, for the states of cognitive impairment and pain, larger proportions rated the state as unacceptable at all interviews (75% and 37%, respectively) vs acceptable (2% and 12%, respectively). A larger proportion of participants changed their ratings from acceptable to unacceptable (8% and 17%, respectively) vs unacceptable to acceptable (3% and 6%, respectively).

For each functional status trajectory, at least 44% of respondents provided the same rating over time for the state of severe functional impairment (**Table 3**). Among those who had a decline in functional status, 27% changed their rating from unacceptable to acceptable, whereas 9% changed their rating from acceptable to unacceptable.

MULTIVARIABLE CORRELATES OF CHANGES IN HEALTH STATE RATINGS

The likelihood of patients' rating the states of mild and severe functional status impairment as acceptable increased significantly over time (**Table 4**). In contrast, the likelihood of rating the state of cognitive impairment as acceptable decreased significantly over time. The likelihood of rating the state of severe pain as acceptable did not change significantly over time.

Patients with greater IADL disability were more likely to rate the states of functional impairment as acceptable, with a 23% (95% confidence interval, 8-40) increase in the odds of rating the state of mild impairment and a 23% (95% confidence interval, 11%-37%) increase in the odds of rating the state of severe impairment as acceptable for each additional IADL disability (Table 4). However, an increase in IADL disabilities was not associated with the ratings for cognitive impairment or pain. Patients who had moderate or severe pain were more likely to rate the state of severe pain as acceptable (odds ratio, 2.6; 95% confidence interval, 1.6-4.2) than those who did not have moderate or severe pain. However, having pain was not associated with the ratings for functional or cognitive impairment.

COMMENT

The results of this study illustrate that for some older, seriously ill persons, changes in their health are associ-

Table 2. Trajectories of Health State Ratings*

Health State	Trajectory of Ratings, No. (%)				
	Acceptable Throughout	Unacceptable Throughout	Acceptable to Unacceptable	Unacceptable to Acceptable	Variable
Unable to leave house	106 (56)	16 (8)	11 (6)	36 (19)	20 (11)
Only able to get from bed to chair; requires assistance with bathing and dressing	61 (32)	36 (19)	12 (6)	38 (20)	42 (22)
Severe memory problems; unable to recognize family	4 (2)	142 (75)	16 (8)	5 (3)	22 (12)
Daily pain (eg, like having a broken bone or appendicitis)	22 (12)	69 (37)	33 (17)	12 (6)	53 (28)

*Based on 189 participants who participated in at least 1 follow-up interview.

Table 3. Trajectories of Health State Rating for State of Being Confined to Going From Bed to Chair According to Trajectories of Functional Status*

Patient's Functional Status	Trajectory of Ratings for Severe Functional Impairment, No. (%)				
	Acceptable Throughout	Unacceptable Throughout	Acceptable to Unacceptable	Unacceptable to Acceptable	Variable
Unchanged (n = 22)	8 (36)	8 (36)	0	5 (23)	1 (5)
Improved (n = 17)	3 (18)	7 (41)	3 (18)	2 (12)	2 (12)
Declined (n = 70)	21 (30)	10 (14)	6 (9)	19 (27)	14 (20)
Other (n = 80)	29 (36)	11 (14)	3 (4)	12 (15)	25 (31)

*Based on 189 participants who participated in at least 1 follow-up interview.

Table 4. Factors Associated With a Health State Rating of Acceptable Among All 226 Participants*

Variable	Health State			
	Unable to Leave House	Able to Go From Bed to Chair	Unable to Recognize Family	Severe Pain
Time, mo	1.11 (1.06-1.16)	1.06 (1.03-1.09)	0.95 (0.91-0.99)	0.98 (0.96-1.01)
Nonwhite race	1.16 (0.24-5.50)	1.70 (0.46-6.27)	3.63 (0.98-13.5)	0.96 (0.27-3.48)
Better than high school education	0.38 (0.15-0.98)	0.48 (0.22-10.4)		
Disease diagnosis				
Congestive heart failure	0.29 (0.10-0.90)	0.39 (0.16-0.92)		
Cancer	0.42 (0.14-1.27)	0.67 (0.28-1.61)		
Self-rated health: excellent, very good, or good	2.14 (1.14-4.02)			
Self-rated quality of life: best possible or good		2.41 (1.47-3.94)	2.23 (1.15-4.35)	2.53 (1.58-4.03)
Depressed	1.81 (0.96-3.43)	2.46 (1.48-4.09)		
Has living will			0.43 (0.20-0.91)	0.41 (0.22-0.74)
Self-rated life expectancy				
<2 y	0.68 (0.27-1.70)	0.86 (0.40-1.82)		
Uncertain	1.90 (0.94-3.85)	2.15 (1.24-3.70)		
Increased IADLs disability	1.23 (1.08-1.40)	1.23 (1.11-1.37)		
Moderate or severe pain				2.55 (1.56-4.19)

Abbreviation: IADL, instrumental activity of daily living.

*Data are given as odds ratio (95% confidence interval).

ated with changes in their valuations of the outcomes that may result from treatment of their illness. Those patients who experienced a decline in IADLs were more likely to rate more severe functional disability as an acceptable outcome of therapy than were those who did not experience such a decline. Similarly, those who had moderate or severe pain were more likely to rate severe pain as an acceptable outcome of therapy than were those who had no pain or mild pain. Changes in the valua-

tions of health states resulting from treatment are specific to the state itself. Even after accounting for changes in functional status and for sociodemographic and other health and psychosocial characteristics, the acceptability of functional disability increased with time, whereas the acceptability of severe cognitive impairment decreased. However, in absolute terms, most participants did not change their ratings of the acceptability of these health states.

Although this study focused on eliciting patients' valuations of health states, it assessed these valuations in the context of whether the patient would choose to have therapy resulting in the given health state. Most previous studies have examined the relationship between clinical status and preferences for specific treatment interventions. Several of these studies demonstrate a relationship between declining health and a greater likelihood of a preference for high-burden life-sustaining treatment.^{12,18} These studies suggest that declining health status is associated with a greater willingness to bear the burdens of therapy. By systematically evaluating the attitudes of older persons experiencing a decline in their health toward a variety of health states, this study suggests that an increased desire to undergo therapy results, at least in part, from the willingness to tolerate diminished states of health, a finding that confirms previous studies.^{34,35} These findings are consistent with the theory of response shift, whereby patients change their self-evaluation of quality of life with changes in their health status.³⁶ This concept is further supported by the finding that higher self-rated quality of life, independent of pain, function, or other markers of health, was associated with a greater likelihood of rating several of the health states as acceptable.

The results of this study pose a serious challenge to the instructional form of advance care planning. The main purpose of these instructions is to allow patients to express their preferences for care in the case of future circumstances in which they are unable to speak for themselves. This presupposes that patients' projections of the treatment they want for themselves in some future state accurately reflect how they would feel in that state. However, the findings of this study illustrate that some patients cannot accurately predict their future valuations. This limitation is well recognized in certain fields, such as psychology³⁷ and decision making,³⁸ but it has not been a prominent part of considerations about advance care planning.

The problems with predicting future hypothetical states of health have led some to conclude that instructional advance directives are a misguided means of care planning.³⁹ However, the methods we used to demonstrate the problem of predicting future health states provide a partial solution to the problem. Many patients were still able to think about and express their preferences regarding these states after experiencing a change in their health status. This finding implies that if advance care planning is conducted as a process over time, in which patients are asked to reflect on their preferences after experiencing a change in their health, they will have the opportunity to reflect on how their preferences may be changing. In addition, the appointment of a health care proxy, another form of advance care planning, is not dependent on patients' ability to predict future states of health. The finding of changes in preferences supports the notion of allowing surrogates leeway in the interpretation of advance directives, an approach that is endorsed by most patients.^{40,41}

Because the study examined the preferences of patients with advanced illness, missing data are unavoidable. The largest cause of missing data in the study was death. It is unclear whether these data are missing in the sense that this term is traditionally used, since these data,

along with the data from participants who became cognitively impaired or more acutely ill, are not recoverable. However, there were also missing data from participants who dropped out of the study for other reasons or who failed to consent to a second year of participation. The issue of missing data in longitudinal research is one of current investigation, and there are no easy or straightforward methods for assessing the effects of missing data. Therefore, we cannot know whether these missing data introduce some bias into the results. The high overall rates of participation and completeness of data collection among patients who remained in the study suggest that data collection was as complete as possible in this challenging population.

The study population included only a few nonwhite participants. Because there was a trend for nonwhite race to be associated with ratings of the acceptability of health states, the findings of this study regarding the rates of different trajectories of health state ratings may not be applicable to all populations of older persons with advanced chronic illness. Further, this study leaves unanswered the important question of the reasons why valuations of health states change over time.⁴² Changes in older persons' treatment preferences over time and the association between changes in older persons' health and treatment preferences highlight the need for repeated assessments of these preferences.

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Correspondence: Terri R. Fried, MD, Clinical Epidemiology Research Center, VA Connecticut Healthcare System, 950 Campbell Ave, CERC 151B, West Haven, CT 06516 (terri.fried@yale.edu).

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